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Respite Care Insights on Federal, State, and Private Sector Involvement

Statement of
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Before the
Subcommittee on Select Education
Committee on Education and Labor
House of Representatives

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Respite Care: Insights on Federal, State, and Private Sector Involvement

GAO's testimony focuses on preliminary results from our respite care study at the national and state level. We collected information on federal government and national organization activities and surveyed programs offering respite care in 5 states: California, Indiana, Massachusetts, New York, and Texas. Respite care is temporary relief in the form of child care for family members and other caretakers who are under high levels of stress. Respite care could be targeted, for example, to parents of disabled children, foster parents, and unemployed parents. Its purpose is to relieve temporarily tne stress and, in turn, to prevent abuse and neglect and support family unity.

-- Respite care is a relatively new, often grassroots level service. It often is provided through local chapters of national organizations such as the United Cerebral Palsy Association. We have identified 6 such organizations with 257 local affiliates providing respite care services, but have been unable to determine the number of families benefitting from their services.

-- Federal involvement in respite care is minimal, occurring mostly through Department of Health and Human Services demonstration grants. Since 1983, HHS has awarded 47 such grants, but funding totaled only $6.5 million. Information on funding from other HHS sources which could be used for respite care was not available. Within the Department of Defense, the Army has the most extensive formal program for providing respite care for service families.

-- While state governments in the states we surveyed are supporting respite care, with little federal assistance, the programs vary greatly in size and funding. In 1988, for example, Massachusetts spent $18.5 million on respite care compared with Indiana's $1.1 million. (The two states have comparable numbers of children under age 18 and handicapped children, rough measures of respite care target groups.) Overall, the programs are new--most began after 1980--and often provide services in addition to respite care. Most provide care at no charge to the family, but little information is available on the characteristics of families served.

-- Little research has been directed at determining respite care's effects, for example, on reducing abuse and neglect. As a first step toward evaluation, programs need to uniformly collect information on respite care services, recipient families, and costs.

Mr. Chairman and Members of the Subcommittee:

I am pleased to provide you with preliminary information from our respite care study requested by your Subcommittee and the Select Committee on Children, Youth, and Families. My statement addresses the nature of national association and federal involvement in respite care, state-level programs, focusing on California, New York, Massachusetts, Indiana, and Texas, and the extent of respite care research and evaluation.

We collected program data and interviewed national association and federal officials responsible for respite care. In the states I mentioned, we conducted a telephone survey to collect program information. We also surveyed the respite care literature and talked with area experts.

WHAT IS RESPITE CARE?

Respite care is temporary relief in the form of child care for family members and other caretakers who are under high levels of stress. Respite care could be targeted, for example, to parents of disabled children, foster parents, and unemployed parents. Its purpose is to relieve temporarily the stress and, in turn, to prevent abuse and neglect and support family unity. High levels of stress within a family, whether caused by the burdens of caring for a disabled child or such factors as financial worries, are strongly linked with child abuse. Such abuse, neglect, or just the family's inability to cope with the child may lead to the child's placement in an institution or foster care. Respite care seeks to support the family as a whole by providing a break for parents and a safe place for the child for a brief time.

Respite care has several characteristics. It is temporary and is directed at the parent or other caretaker--though the child's needs may require a special skills respite care provider. It can

be planned and act as a preventive service before a crisis is reached, but it also can be an emergency service such as a crisis nursery, which specializes in providing short-term crisis care to abused and neglected children.

Respite care as a recognized service is relatively new. As with many social services, it originated at the grassroots level. The need for family support services, such as respite care, became apparent in the early 1970's following the movement to allow disabled persons, particularly children, to remain with their families instead of being placed in an institution. Crisis nurseries began at about the same time. While respite care is most widely used in the disability area, child welfare agencies also may include it among their services.

Currently, most respite care activity appears to be in the private sector, provided through local chapters of national organizations. Federal involvement occurs mostly through demonstration grants such as those funded through the legislation you are considering reauthorizing. Our work in 5 states found that while state governments are supporting respite care, with little federal assistance, programs vary greatly in size and funding. Little research has been directed at determining respite care's effects, such as on reducing abuse and neglect. As a first step, programs need to work toward a uniform definition and collect information on services, recipient families, and costs.

NATIONAL ORGANIZATIONS: GRASSROOTS EFFORTS

Support for respite care often comes from national organizations or associations involved in social services. These organizations' local chapters frequently are the focus for grassroots activity, since they respond to community needs. We

identified at least six organizations that had a total of 257 local chapters with respite care services. However, these organizations did not collect information on how many families have benefitted from these services.

These organizations use different approaches for providing respite care. For example, the National Council on Aging uses its Family Friend Program to match older volunteers with chronically ill and disabled children. The volunteers visit the children at least once a week in their homes, providing psychological and social support to the children, parents, and other family members.

The National Down Syndrome Society has a respite care program which places these children with volunteer host families for one weekend every six weeks over a one year period. Along with providing regular respite care for the children's parents, the program seeks to foster independence in the children and educate host families and communities about Down Syndrome.

LIMITED FEDERAL INVOLVEMENT

Federal involvement in this relatively young human service is limited largely to demonstration grants. The extent to which permanent funding sources are used for respite care is harder to identify, but, except for the ACTION agency, appears minimal.

As expected, much of the activity is by the Department of Health and Human Services. The 32 temporary care for handicapped children and crisis nursery grants make up the largest federal source of support for which we could identify funding. Since 1983, HHS has awarded 15 other grants for respite care, only one of which is still active. Total funding for all 47 grants,

however, is only $6.5 million. Although other HHS funding sources have been used to provide respite care, information was not available on the amount provided by (1) Medicaid which in some cases finances home and community-based services for disabled individuals, (2) title V of the Social Security Act -- children with special needs, (3) title IV-B of the Social Security Act -- child welfare, and (4) social services block grant.

The ACTION agency has provided one $25,000 grant for a respite care program. ACTION also has provided respite care through its Foster Grandparent Program, whose 328 local programs hire low-income elderly people to act as foster grandparents to special needs children. The Department of Education has funded three grants, each for $30,000, to develop respite care educational materials. The Department of Interior has one respite care project at an Indian reservation.

In the Department of Defense, the Family Support program provides some respite care through its Family Advocacy and Exceptional Family Members (Handicapped) components. Within the Department of Defense, the Army has the most extensive formal program, with respite care being one of several family support services provided. In the United States and overseas, the Army has (1) 99 installation programs, (2) 133 programs located off its installations, and (3) 107 foster care programs. Information on funding and numbers of families served is not routinely collected.

The Navy has programs at six locations worldwide which together spend about $62,000 annually on respite care-related activities. The Air Force and the Marine Corps have no formal programs, but officials told us these services use volunteers, community resources, and nonappropriated funds to support respite care

functions. They also use child development centers for respite care on an infrequent basis.

STATE RESPITE CARE PROGRAMS VARY WIDELY

Our survey of 24 programs in 5 states found extreme variation in number of families served and funding levels. Several states have programs with significant state support. Other programs are much more modest. Overall, most programs are relatively new and, in keeping with the picture of limited federal involvement, receive little federal funding.

Program Administration

We found multiple agencies, as many as four in a state, administering the programs. Departments of Human/Social Services and Mental Health together administered two-thirds of the programs. Three-fourths of the programs began providing services after 1980.

The 19 programs which could provide funding data spent about $44 million on respite care in fiscal year 1988. Ninety-nine percent of the total was state funding. However, states varied widely in their support for respite care. For example, Massachusetts and Indiana have comparable numbers of children under 18 and handicapped children (a rough measure of respite programs' target population). Yet, Massachusetts spent a total of $18.5 million on respite care, compared with Indiana's $1.1 million.

Most programs paid the providers for respite care services. Other funding mechanisms included cash subsidies to parents, direct service provision, and grants to county or local nonprofit agencies.

Eligibility

The programs are split among those that serve multiple target populations and those that are narrowly targeted. Each of the five states has at least one program serving families with a broad range of special needs children. The most frequently targeted group is families with mentally retarded children. Some children, such as severely emotionally disturbed, abused or neglected, and foster children, are less frequently targeted by individual programs.

Other eligibility criteria center on a child's age and family income. Almost all of the programs allow families to receive respite care from the time a child is born. Some programs place no upper age limits for eligibility. Others end eligibility at ages ranging from 18 and 24 and still others serve only children of certain age ranges below age 18.

Most of the 24 programs have no income ceilings above which a family would be ineligible for respite care services. A few programs have family income ceilings that would allow most middle-class families to qualify for assistance. One serves families in the Supplemental Security Income program, thus coming under its eligibility requirements.

Two-thirds of the programs provide services at no charge to eligible recipients. Programs requiring a family contribution require partial payment based on a sliding scale according to ability to pay, a flat rate, or a formula based on family net worth.

Service Availability

The 12 programs reporting data on recipient families show great variation in the extent of respite care provision. Programs operated statewide ranged from 3 to 15,000 families served in 1987 or 1988. Other programs, those operating at a limited number of locations, ranged from 2 to 51 families. Programs could provide very little information on service demand versus availability or recipient characteristics.

Although respite care is designed to be temporary, program rules set few specific limits on the amount of respite care available to eligible families. For example, respite care is generally available year round. Only a few programs specifically limit the number of service hours or days that can be used in a given period. However, some programs reported that available funding could limit the amount of respite care they provide to a family.

Respite care is only one of several services provided to families by most of the 24 programs. Additional services included (1) counseling, (2) homemaker, (3) recreational, and (4) nursing care. A third of the programs provided respite care only.

Most programs provided respite care services in the home. Respite caregivers in the home setting included those skilled in services such as nursing care, homemaker, baby sitting, companionship, and home health care.

Many programs also provided respite care outside the home. The most frequently used settings outside the home were private family homes, day care centers, and residential and respite care facilities. The services most frequently provided in these settings were nursing care, personal care, and camping.

The programs surveyed generally do not pay for training respite care providers. However, the state programs required providers to be licensed or certified by the respective licensing authorities for their individual specialty, such as nursing.

RESPITE CARE RESEARCH AND EVALUATION

We could identify little research on respite care's effects, such as on reducing stress or child abuse and neglect. To date our literature survey has found no significant studies of respite care. The lack of research may be explained by respite care's relatively recent emergence as a needed, available service and the small size and funding of many respite programs. Also, because respite care often is one of several services offered by a program, its effects are difficult to isolate from those of the other services.

We also reviewed the applications for demonstration grants awarded under the 1986 Temporary Child Care for Handicapped Children and Crisis Nurseries Act to determine how evaluations will be done. Only about half of these applications contain detailed plans. The Department of Health and Human Services plans to convene a group of project staff in May to develop a data collection and evaluation strategy for the projects.

In concluding my remarks, I would like to suggest some areas which should be considered in the evaluation of respite care programs. Our work shows that only limited information is available on respite care program characteristics and recipient demographics. But basic program information is needed to properly plan, provide, and evaluate these services--

notwithstanding the complications brought about by respite care's inclusion as one of many services provided by a program.

Thus, as a first step in the evaluative process, programs need to work toward a common respite care service definition and uniformly collect, analyze, and report in a consistent way such information as:

-- Types and amounts of various services provided as respite care;

-- Number of families receiving services;

-- Recipient demographic data; and

-- Cost of various types of services.

Finally, as part of the evaluation process, programs could survey families to measure their satisfaction with services provided. The types of information I have mentioned would allow better analysis to determine how respite care services are being delivered, to whom, and the extent to which parents and other caretakers feel their needs are being met.

Mr. Chairman, this concludes my prepared remarks. I would be happy to answer any questions.

APPENDIX I

NATIONAL ORGANIZATIONS INVOLVED IN RESPITE CARE

Table I.1: Summary of National Organizations Involved in Respite Care

Organization	Number of Local Chapters Providing Respite Care	Number of States Covered
Visiting Nurses Association	87	29
Camp Fire	73	30
United Cerebral Palsy Association	46	18
Easter Seal Society	37	26
National Council on Aging	10	9
National Down Syndrome Society	4	3
TOTAL	257	

APPENDIX I

NATIONAL ORGANIZATIONS INVOLVED IN RESPITE CARE

Table I.2: Local Chapters of National Organizations With Respite Care Programs by State

	Easter Seal Society	Camp Fire[a]	UCPA[b]	Down Syndrome	Council On Aging[c]	Visiting Nurses
Alabama	1	1	4			1
Alaska						
Arizona						
Arkansas	1					1
California	1	9	4	1	2	7
Colorado		2				4
Connecticut	1	1			1	
Delaware	1		2			1
District of Columbia	1				1	1
Florida		3	3	2	1	9
Georgia		1	1			1
Hawaii	3					
Idaho						
Illinois	2	4	2			6
Indiana		2				5
Iowa	2	3				
Kansas		1				
Kentucky	1					1
Louisiana	1	3	1			
Maine	1	1				1
Maryland		1	2			
Massachusetts		1				3
Michigan	1	4				7
Minnesota		2				
Mississippi						
Missouri		1	1			5
Montana						
Nebraska		1			1	1
Nevada	1		1			
New Hampshire	1	1				1
New Jersey		1	3			2
New Mexico						
New York	1	2	8	1		4
North Carolina	2					
North Dakota	1					
Ohio	4	1	2		1	2
Oklahoma		1				1
Oregon	2	4				1
Pennsylvania	1	2	4			8
Rhode Island		1				2
South Carolina						
South Dakota	1					
Tennessee	1	1	1			2
Texas	1	8			1	5
Utah	1	1			1	1
Vermont						
Virginia	3					
Washington		9				1
West Virginia						
Wisconsin	1		6		1	3
Wyoming		1				
Puerto Rico						
Totals	37	73	46	4	10	87

[a]Special Sitters Program Data Ordered By Local Affiliates
[b]United Cerebral Palsy Association
[c]Family Friends Program

APPENDIX II

FEDERAL RESPITE CARE DEMONSTRATION GRANTS

Table II.1: Funding for Federal Respite Care Demonstration Grants

Agency	Number of Grants	Total Funding
Health and Human Services		
Temporary Child Care	16	$2,348,336
Crisis Nurseries	16	2,413,508
Other	15	1,753,444
Subtotal	47	6,515,288
Education	3	90,000
ACTION	1	25,000
TOTAL	51	$6,630,288

APPENDIX II

FEDERAL RESPITE CARE DEMONSTRATION GRANTS

Table II.2: Federal Grants For Respite Care Activities By Federal Agency and State

	Public Law 99-401 Section 203[a]	Public Law 99-401 Section 204[b]	Other HHS Grants	Dept. of Education	Action
Alabama	1				
Alaska			1		
Arizona		1			
Arkansas	1				
California	1	1	1	1	
Colorado	1		1		
Connecticut					
Delaware			1		
District of Columbia			1	1	
Florida	1	1			
Georgia					
Hawaii		1			
Idaho	1				
Illinois	1	1			
Indiana					
Iowa					
Kansas	1				
Kentucky					
Louisiana					
Maine			1		
Maryland		1			
Massachusetts	1		2	1	
Michigan	1				
Minnesota					
Mississippi					
Missouri					
Montana					
Nebraska	1		1		
Nevada					
New Hampshire	1				
New Jersey		1			
New Mexico			1		
New York	1	3			1
North Carolina	1	1			
North Dakota		1			
Ohio		1			
Oklahoma					
Oregon		1			
Pennsylvania		1			
Rhode Island					
South Carolina					
South Dakota					
Tennessee	1				
Texas					
Utah			1		
Vermont		1			
Virginia	1				
Washington		1	1		
West Virginia					
Wisconsin			1		
Wyoming					
Puerto Rico	—	1	—	—	—
Totals	16	16	15	3	1

[a]Temporary Child Care for Handicapped and Chronically Ill Children.
[b]Crisis Nurseries.

APPENDIX III

CHARACTERISTICS OF STATE RESPITE CARE PROGRAMS

Table III.1: Summary of Characteristics of Programs in Five States Offering Respite Care

Number of programs = 24

Characteristic	Number of Programs
Administering Agency:	
Social/Human Services	8
Mental Health/Retardation	8
Health	4
Welfare	2
Developmental Disabilities	1
Education	1
Year Services Began:	
Before 1980	4
1980 and after	18
Unknown	2
Geographic Coverage:	
Statewide	16
Limited	8
Target Group Coverage[a]:	
Broad	9
Limited	15
Services:	
In-Home Only	5
Out-of-Home Only	4
Both	15

[a]"Broad" targeting means the program covered the developmentally disabled or all or most of the following groups: Mentally retarded, physically handicapped, chronically ill, abused/neglected, visually impaired or blind, speech or hearing impaired, foster children. "Limited" targeting means the program served only one or two of those groups.

Table III.2: Characteristics of Programs in Five States Offering Respite Care (1988)

State/ Program No.	Administering Agency	Year Began	Statewide Services	Target Group Coverage[a]	Funding	Families Served	Services In-Home	Services Out-of-Home
CALIFORNIA								
One	Education	1984	Yes	Broad	$1,069,000	[b]	Yes	Yes
Two	Devel. Disab.	1977	Yes	Broad	7,528,496	[b]	Yes	Yes
Three	Social Serv.	1983	Yes	Limited	[b]	[b]	Yes	Yes
Four	Health	1985	No	Limited	272,000	25	No	Yes
INDIANA								
One	Human Serv.	1987	No	Limited	150,000	[b]	No	Yes
Two	Human Serv.	1988	No	Limited	3,044	5	Yes	No
Three	Mental Health	1978	Yes	Limited	850,000	950	Yes	Yes
Four	Welfare	1977	Yes	Broad	136,696	[b]	Yes	Yes
MASSACHUSETTS								
One	Health	1985	No	Broad	40,000	41	No	Yes
Two	Health	1975	Yes	Broad	400,000	188	Yes	No
Three	Mental Retard.	1984	Yes	Limited	3,000,000	[b]	Yes	Yes
Four	Mental Retard.	1980	Yes	Broad	8,000,000	6,300	Yes	Yes
Five	Social Serv.	1982	Yes	Broad	7,000,000	3,700	Yes	Yes
Six	Welfare	1984	No	Limited	39,427	[b]	Yes	Yes
NEW YORK								
One	Mental Health	1983	Yes	Broad	15,000,000	15,000	Yes	Yes
Two	Mental Health	[b]	Yes	Limited	237,000	[b]	Yes	No
Three	Health	1985	No	Limited	118,000	35	Yes	No
Four	Social Serv.	1985	Yes	Limited	[b]	[b]	Yes	Yes
TEXAS								
One	Human Serv.	1988	Yes	Limited	19,994	3	Yes	No
Two	Human Serv.	1988	No	Broad	7,200	2	Yes	Yes
Three	Human Serv.	1985	No	Limited	23,880	51	Yes	Yes
Four	Mental Health	1988	Yes	Limited	[b]	[b]	Yes	Yes
Five	Mental Health	1985	Yes	Limited	[b]	[b]	Yes	Yes
Six	Mental Health	[b]	Yes	Limited	[b]	[b]	No	Yes

[a]"Broad" targeting means the program covered the developmentally disabled or all or most of the following groups: Mentally retarded, physically handicapped, chronically ill, abused/neglected, visually impaired or blind, speech or hearing impaired, foster children. "Limited" targeting means the program served only one or two of those groups.

[b]Not available.